

103^D CONGRESS
2^D SESSION

H. R. 5173

To amend the Public Health Service Act to establish within the Office of the Director of the National Institutes of Health an Office for Rare Disease Research.

IN THE HOUSE OF REPRESENTATIVES

OCTOBER 4, 1994

Mr. WYDEN introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to establish within the Office of the Director of the National Institutes of Health an Office for Rare Disease Research.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Office for Rare Disease
5 Research Act of 1994”.

1 **SEC. 2. ESTABLISHMENT OF OFFICE FOR RARE DISEASE**
2 **RESEARCH.**

3 Part A of title IV of the Public Health Service Act
4 (42 U.S.C. 281 et seq.) is amended by adding at the end
5 thereof the following new section:

6 **“SEC. 404F. OFFICE FOR RARE DISEASE RESEARCH.**

7 “(a) ESTABLISHMENT.—There is established within
8 the Office of the Director of the National Institutes of
9 Health an office to be known as the Office for Rare Dis-
10 ease Research (in this section referred to as the ‘Office’).
11 The Office shall be headed by a director, who shall be ap-
12 pointed by the Director of the National Institutes of
13 Health.

14 “(b) PURPOSE.—The purpose of the Office is to pro-
15 mote and coordinate the conduct of research on rare dis-
16 eases through a strategic research plan and to establish
17 and manage a rare disease research clinical database.

18 “(c) ADVISORY COUNCIL.—The Secretary shall es-
19 tablish an advisory council for the purpose of providing
20 advice to the director of the Office concerning carrying
21 out the strategic research plan and other duties under this
22 section. Section 222 shall apply to such council to the
23 same extent and in the same manner as such section ap-
24 plies to committees or councils established under such
25 section.

1 “(d) DUTIES.—In carrying out subsection (b), the
2 director of the Office shall—

3 “(1) develop a comprehensive plan for the con-
4 duct and support of research on rare diseases;

5 “(2) coordinate and disseminate information
6 among the institutes and the public on rare diseases;

7 “(3) support research training and encourage
8 the participation of a diversity of individuals in the
9 conduct of rare disease research;

10 “(4) identify projects or research on rare dis-
11 eases that should be conducted or supported by the
12 National Institutes of Health;

13 “(5) develop and maintain a central database
14 on current government sponsored clinical research
15 projects for rare diseases;

16 “(6) determine the need for registries of re-
17 search subjects and epidemiological studies of rare
18 disease populations; and

19 “(7) prepare biennial reports on the activities
20 carried out or to be carried out by the Office and
21 submit such reports to the Secretary and the
22 Congress.”.